

Information and support for families of children with Hydranencephaly

Hydranencephaly Newsletter July 2008

This is our monthly newsletter about Hydranencephaly and the issues a child with Hydranencephaly might face. . Its purpose is to share information on the various aspects of Hydranencephaly as well as to show case our beautiful children. Much of the information presented in the newsletter will originate from the Hydranencephaly Mailing list or group, which is hosted by Yahoo groups.

Topic of the month: Communication for a Child With Hydranencephaly Part 2

Learning to “Read” Your Child (Communication) Part 2

In this edition of the newsletter I’m presenting some more ways to encourage your child to communicate and to help you learn your child’s “language”.

The Hanen course was mentioned in an article in last month’s newsletter. I’m now including 2 principals taught in that course for your information.

For more information and how to find a Hanen program in your area go to:
<http://www.hanen.org/web/Home/tabid/36/Default.aspx> It looks like you have to register to get access to any of the directories. If you are interested in finding a Hanen program for your child you can contact your local Speech/Language Pathologist

activities. It requires a conscious effort to take a moment, often it’s only a few seconds, to **Observe, Wait and Listen** to our child.

Observe

Wait and

Listen



*Taking the time to OWL is the wise way to start.
Consciously taking the time to OWL is the first and most important step in getting to know our child intimately.*

Observe:

As parents, our care and concern for our children and the time we spend with them give us endless opportunities to observe them carefully and get to know and understand them better.

Even when our children don’t use words, we can easily recognize their **feelings or needs**

Chapter 1: Allow Your Child to Lead Know Your Child Intimately

In our desire to care for, to teach and to entertain our child, our natural instinct is to take over. It takes a conscious effort not to anticipate quickly what our child needs, not to tell her what to do, not to choose her play

Table of Contents	
Introduction to the Hanen program	1
Chapter 1: Allow Your Child to Lead	1
Chapter 2: Adapt to Share the Moment	3
The first goal: Intentional communication	4
Communication Example	6
July Birthdays and Sadaversaries	6

when we take the time to observe their:
 focus of attention
 Facial expression
 Body Language



Facial expression



Focus of attention



Body language

But sometimes our children's facial expressions, actions and focus of attention are not clear enough to help us figure out what they are trying to tell us.

- Observing the following subtle cues can be helpful:
- State of alertness
- Rate of breathing
- The pitch, volume, and duration of their sounds.

It takes time and determination to get to know the unique combination of body language and sounds that each child uses to communicate

Wait



When we wait, we give our child the time he needs to express his interests and feelings in his own way.

Waiting for our child to communicate is hard to do!

Our lives keep moving at an increasingly rapid pace, and we have come to feel that a silent moment is an empty moment. As adults, we also feel that it's our duty to teach, test our child's knowledge, and conduct conversation. And so we tend not to wait for our child to express himself. Instead, we try to help in our own adult ways. We talk for our child, answer for our child, and use controlling language (commands and questions).

Taking over is a natural, even instinctive, reaction on our part. However, if we want to help our child learn, we must give him a chance to express himself in his own way.

If we make everything simpler, easier, and faster for ourselves, we may find that we're ignoring the feelings, needs, and curiosity of the child we care for and are concerned about.

Waiting gives us the chance to get to know our child. We can watch for his focus of attention, look at the expression on his face, and listen to the sounds he makes.

Listen



Sound familiar? How many times do we have a conversation with our child where we do all the talking?

When we talk and our child doesn't respond easily, our natural reaction is to fill in all the blanks, answer all the questions, and even comment without leaving a pause.

We think we're making things easier, but we're actually involved in a form of loving sabotage. We don't expect an answer, and our child usually fulfills our expectations by not communicating.

If we listen attentively to our child, our undivided attention will give our child the security and encouragement to make his efforts worthwhile.

If we listen attentively to our child, we will also understand him better and be able to respond more sensitively to him.

It Takes Two To Talk, A Parent's Guide to Helping Children Communicate, Ayala Manolson, Hanen Centre Publication, c 1992, pp 4-7

Chapter 2: Adapt To "Share the Moment"

Be Face To Face

One of the most important things we can do to communicate with our child is also one of the simplest: Position ourselves so that our child can look directly into our eyes.



When we are face-to-face, available and interested, some surprising things happen:

We learn more about our children by being able to observe their facial expressions, focus, state of alertness and skin tone.

Our Children learn more about us. They can see the way our mouth moves to form words and watch our eyes to find out what we're looking at. They can also see and experience our acceptance of their attempts to communicate and our pleasure in "sharing the moment" with them.

We talk with our children, not at our children. Being close together encourages the give and take of communication and puts us in a better position to allow the child to lead.

We've all experienced how hard it is to have a conversation with someone taller or shorter than we are. It's such an effort to make eye contact, and we soon move on to talk to someone we are more comfortable with---someone at our level.

So rather than looming over our child, we can:

- **Bend our knees more**
- **Get down on the floor**
- **Lie on our tummy**
- **Hold our child on our knees**
- **Sit on the floor and give our child the chair.**

We can make it easier and more comfortable for our child to look into our eyes and have conversations with us by adapting our position so we are "face to face".



Let Your Child Know You're Listening Imitate

One of the best ways to connect with very young children who are just beginning to communicate is to imitate their sounds, actions, facial expressions and words. If a child puts his head to one side and we do the same, if he says "uh uh" and we say the same, he will know that we're interested in what he's doing and what he's saying. Chances are we'll make a connection that develops into a conversation.

When in doubt, don't hesitate....Imitate!



Interpret

We get excited about the new sounds and gestures that come from our child. We are quick to interpret them and to assign them the words we think they mean.

When we interpret, it confirms that we've received our child's message. It provides our child with a language model to learn from. We usually think of interpreters in terms of a foreign language, but when we interpret for our child, we're trying to help her speak our language.

When we interpret for our child, we say it as she would if she could.

Interpreting a child who is difficult to understand demands a special kind of detective work.

- Interpreting may mean guessing at what the child's trying to say and putting it into words. Even when we are wrong, our response lets our child know that we are listening.
- Repeat what our child says with a question in our voice encourages her to try again and, perhaps, she can be clearer.
- Explaining that we can't understand and asking our child to show us is another way of confirming our interest.

When all else fails, a sincere expression of our desire to understand and to try again later will let our child know that we appreciate her efforts.

Comment:

Commenting on what we are doing when our child appears interested can be the start of sharing information and everyday activities—e.g., setting the table, washing up, sweeping the floor—and perhaps even getting some “help” in doing them. We also let our child know that we are interested in communicating with her when we comment on what she says or does and **we**

don't change the topic.

Have Conversations — Take Turns

When children are learning to communicate, the more conversations they have, the more turns they get to take and the more opportunities they have to learn.



For a child beginning to communicate, a “turn” can be a look, a gesture or a sound. Or a child's turn can even be as subtle as an intake of breath. It may not seem like much, but by recognizing and accepting our child's way of taking part, we can keep the conversation going.

“Conversation” sounds like such a formal adult word. But all it really is, is a series of turns. We take a turn, the child takes a turn, and then we take another turn. As our child matures, her turns in the conversation will progress to words, phrases and sentences.

The natural give and take of daily life with our children gives us many opportunities to share experiences, take turns, exchange ideas, and have good conversations with them. In the beginning, these conversations help our children experience the joy of sharing what's on their minds. Then they discover that these conversations can provide them with new and useful information about their world.

Chapter 2: Adapt To Share The Moment, It Takes Two to Talk, A Parent's guide to Helping Children Communicate, Ayala Manolson, A Hanen Centre Publication, c 1992. pp 17-19

Note; Not all of the preceding information will work or be attainable for a child with Hydranencephaly. It is presented here for information purposes only. If you want more information about the Hanen program go to: <http://www.hanen.org/> There is a link on the site to help you locate a Hanen therapist in your area.

Here is some more information on encouraging communication for your child.

The first goal: Intentional communication

<http://aac.unl.edu/yaack/d2a.html#d2a1b#d2a1b>

Children all start out as unintentional communicators; that is their behaviors are not intended as communication, but are interpreted by adults as being communicative. For example, crying is interpreted as if the infant was "telling" the parent of a desire for food, even though the crying is involuntary and would have occurred outside of the presence of the parent. Typically, the child next develops into an intentional, but still nonsymbolic, communicator. This is characterized by such actions as reaching, looking at, or pointing towards something to indicate a desire for it. Finally, the child develops symbolic communication skills, the most prevalent being spoken language.

For a child with disabilities who is not yet an intentional communicator, a communication program should first aim at teaching intentionality. Essentially, this means teaching the child that certain behaviors (i.e. communicative ones) get specific responses, and that, through these, the child can deliberately exert some control over his or her life. At this point the child is pre-symbolic, so pictures and other symbols are not appropriate. Furthermore, it is often recommended that behaviors already in the child's repertoire be used, rather than teaching new behaviors in addition to new cognitive skills. For example, reaching, looking, pointing, or facial expressions may already be regularly used by the child. The objective, then, would be to assist the child in using them for the purpose of communication (Van Tatenhove, 1987).

General recommendations for teaching a child intentional communication include the following.

- Become aware of how the child is currently communicating, even though it is still unintentional. Identify communicative behaviors over which the child could potentially develop control, such as movements, facial expressions, or vocalizations. Respond to these as if they were conscious actions. Responses should be as consistent as possible. The child will learn to connect the behavior with its response and begin to produce

the behavior in order to elicit the response.

- Make statements that comment on what the child's behavior is communicating. For example, say to the child "You are raising your arms. That means 'up.' I will pick you up" (Van Tatenhove, 1987). Besides helping the child to realize that raising his or her arms results in being picked up, this can serve to increase the child's understanding of speech (called receptive language). It also helps the parent or teacher to be consistent in responding to the child's communicative behaviors.
- Focus on communicative behaviors to which the natural response is something that is highly motivating to the child. For example, if the child enjoys attention, then a social response is good because it will prolong the interaction. Children may also request (unintentionally) toys or food, and be given it. The child is initially producing the behavior at random, but eventually should come to connect the behavior with its consequence or reward. (Schweigert, 1989).
- Acknowledge and respond to every communicative attempt by the child. Try to respond in a consistent manner even in different situations. This may mean having to inform others what a behavior or action by the child is communicating, and how to respond to it. A "dictionary" in which communicative behaviors and actions by the child, the situations in which they typically occur, and what the response should be are all written down can help different partners coordinate their interactions with the child (Reichle, 1997).
- Activities and routines can be very useful in teaching intentional communication. Create structured, predictable routines that can be centered around daily events such as mealtime, bath time, dressing, toileting and bedtime. The idea is that the child will eventually begin to anticipate the different steps in the activities and routines. This may be indicated by facial expressions or movements that indicate pleasure, dislike or an awareness of what is going to happen next. Simple, repetition-based games which most young children enjoy are also excellent in developing early communication skills. Choose games that are short and easy,

involve taking turns with a partner, and can be varied slightly. Examples of such games are peek-a-boo, or "Row, Row, Row Your Boat" in which partners sit facing each other, holding hands and rocking back and forth. While playing these games, pause periodically to see if the child in some way indicates a desire for more. (See Activities and routines as teaching tools.)

- Try to keep the child informed of who is present and what is happening. For children with dual sensory impairments (i.e. disabilities in both vision and hearing), or minimal environmental awareness, Beukelman and Mirinda suggest that whenever a new partner initiates a routine the following information should always be provided to the child through verbal, tactile, movement-based, olfactory, or other modes:
 - a. A greeting to the child by and identification of the new partner. (For example, an adult may always wear a large watch. Whenever this adult encounters the child, the adult can greet the child verbally and, at the same time, have the child feel the watch.)
 - b. Identification of the new routine. (For example, the child may always be given a wet washcloth to touch prior to being given a bath. This becomes the signal that it is bath time.)
 - c. Identification of available choices. (For example, make the child aware of the different options available using whatever signals have already been established with the child.

The end of the routine should always include:

- a. Indication that the routine is over.
- b. Indication that the partner is leaving (if that is the case).

One more example of how a child with Hydranencephaly can communicate:

Xavier, 9 mos.: Xavier communicates, too, mostly by smiling and laughing when happy, fussing constantly for bubbles, whining for messy bum, licking lips for hungry, startling for unexpected sounds, and looking around if he hears the voice of someone he wants to visit with.

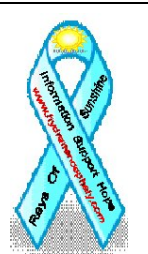
July Birthdays

Laylah: 7/1/05
 Chase: 7/3/96
 Leo: 7/10/91
 Isabella: 7/12/01
 Bridget: 7/14/02
 Andrew: 7/18/89
 Ged: 7/18/05
 Megan: 7/24/96
 Rachel: 7/27/93
 Kemmer: 7/28/93

July "Sadaversaries"

(birthdays and anniversary dates for children who have died)

David: **7/1/88**-9/18/06
 Kristen: **7/4/82**-9/10/03
 Jacob N.: 3/28/00-**7/9/00**
 Travis G.: **7/10/84**-2/23/93
 Emmilee Rose: **7/10/04-7/14/04**
 Mariposa: **7/14/00-7/14/00**
 Mariah: **7/14/00**-4/14/01
 Bakhita: **7/17/03**-9/9/03
 James: **7/22/99**-8/30/01
 Paiten: **7/22/04**-2/19/06
 Melissa: **7/23/81**-1/4/97
 Paul: **7/26/93**-5/14/03
 Jake: 10/4/01-**7/30/02**



Help raise awareness of Hydranencephaly by purchasing a magnetic car ribbon.

Please go to: <http://www.hydranencephaly.com/awarenessribbons.htm> for information on how to order yours.

Do you have a story of how you've responded to someone saying negative things about your child. If so, please send it to me at: angelbearmom@shaw.ca

Next month (August): Tube Feeding: Pros and Cons, Making the Decision for Tube feeding.

September: Traveling with your child with Hydranencephaly

If you have any experiences you'd like to share on either topic please contact me at: angelbearmom@shaw.ca